Symptom management planning for children’s palliative care

Why write a Symptom Management Plan?

Good symptom management planning has been shown to reduce the need for out of hours support as practitioners have considered in advance and prepared families and other carers how a child’s symptoms may progress and have a plan in place to deal with them. This is particularly important if the child is cared for in the community.

Symptom management planning for children’s palliative care is a skilled task – developed based on good assessment, sound clinical judgement and specialist knowledge. The plan considers ‘probability rather than certainty’. An effective plan may take many hours of preparation, but the potential impact is considerable. Parents reassured that there is a ‘next step’ and their child should not ‘suffer’ due to symptoms that are out of control; professionals equally reassured that they have one agreed plan to follow.

Potential challenges

Parents are generally very receptive to Symptom Management Plans (SMPs), but care and sensitivity are essential in sharing the details of these plans with families as the SMP will contain reference to distressing symptoms and situations including for example decisions made about resuscitation. Discussion of the SMP can be a very useful opportunity to prepare families for what may happen, but it is important to stress that each child will not develop every symptom.

Engaging other relevant professionals is important as they may know the child and their family better than you. It is important to include contact details for symptom management advice as SMP may not cover all possibilities.

Model for a Symptom Management Plan

Symptom Management Plans (SMPs) are individualised plans written specifically for each child hence creating one template that covers all potential situations is not possible. Attached is an SMP model which has been designed to assist practitioners during End of Life Care. This model proposes a format commencing with an overview of the child’s details such as weight, diagnoses, presenting problems including allergies and current medication. Details about managing the child’s specific symptoms then follow. The template suggests a number of common symptoms, however not every child will have the same symptoms; it is the responsibility of the practitioner to document the relevant symptoms for that child and to consider both pharmacological and non-pharmacological approaches.

The most common symptom management problems can be grouped as follows **:

- Pain
- Respiratory eg breathlessness, cough, secretions, hiccups, haemoptysis, pleural effusions
- Gastrointestinal eg nausea and vomiting, constipation, diarrhoea, obstruction, anorexia, ascites, mouth care
- Neurological eg seizures, agitation, delirium, raised intracranial pressure, spinal cord compression, muscle spasm
- Urinary
- Skin eg pruritis, lymphoedema, malignant wound care
- Haematological eg anaemia, thrombocytopenia, bleeding, thrombosis
• Psychological eg anxiety, depression
• Electrolyte eg hypocalcaemia, uraemia

**Principles of symptom management**

1. Remember to consider the whole patient
Symptoms are never purely physical or purely psychological and all symptoms and treatments will have an impact on the child/YP and their families

2. Assessment
A holistic and M/D approach to child/YP assessment should be used. Assessment is a process and not a single event with the child/YP and their family central and involved wherever possible. Information should be systematically gathered, recorded, shared and reviewed with consent of the child/YP and their family.

3. Evaluate symptoms thoroughly
Consider potential causes and remember to consider causes other than the primary diagnosis. Also explore the impact of the symptom on the child/YP’s quality of life.

4. Review early treatments
Find out what has been tried previously and whether it was used optimally. Also consider skin, eye and bowel and bladder care.

5. Effectively communicate with both the child/YP and their family
Explain the reasons for the symptoms and management strategies in simple terms and avoid medical jargon. Discuss treatment options with the child/YP and their family and involve them in the management plan.

6. Correct the correctable
Correct treatment as long as it is practical, not overly burdensome and in the child/YP best interests

7. Consider the non - pharmacological treatment
Ensure that both the pharmacological and non-pharmacological methods of treatment are considered within your plans. Non-pharmacological might include using certain non invasive nursing or therapy techniques such as anxiety management, simple or different positioning for care, use of equipment such as TENS, pillows or different beds and use of relaxation techniques/complementary therapy such as music and massage.

8. Keep treatment simple and prescribe prophylactically
When using drug treatment for persistent symptoms keep drug treatments as simple as possible. Remember to prescribe and administer ‘regular’ and also ‘as required’ medication. Pre-empt possible side effects eg laxatives for child/YP on opiates.

9. Review
Review relevant interventions regularly and adjust treatment accordingly.

10. Plan in advance
Ensure that the child/YP has a written Symptom Management Plan and documentation of their future wishes including resuscitation status. Ensure that anticipatory or emergency drugs are prescribed and available and that other staff are informed of these plans.
11. **Multidisciplinary working**
There should be clarity of roles, responsibilities and lines of communication, both for the family and between different professionals involved.

12. **Ask for help**
A child will have a named nurse responsible for their Symptom Management Plan. There should be a Nurse Specialist ‘on call’ to advise, assess and support other professionals as well as the child and their family. Advice is also available from Consultant Paediatric Oncologist, Haematologist, and Palliative Care Specialist Paediatricians.

**Consider your audience**
For the plan to be most effective it will need to be used in all the settings the child frequents eg home, school, short break providers as well as other health providers. Careful consideration should be given to the wording of the plan ensuring that descriptions of care are accessible to all users including families.

**Review**
Prior to use a plan should be agreed by the child’s consultant, it should then be shared with all involved professionals, including GP and with the child’s parents. Once in place the plan should undergo frequent review to ensure it continues to be relevant. It is essential that any changes made to the plan are clearly communicated to all those who have received a version hence version control and circulation is important.

**Resources**


6. NICE Guidelines eg Constipation, Epilepsy and Spasticity
Appendix One: Questions to think about each visit/meeting.

Assessment questions could include:

- Respiratory: has there been a change since last meeting? Increased stridor stomach breathing, coughing
- What has the child’s colour been like?
- Has the child had episodes of arching, screaming and breath holding? Have these changed or increased?
- What has the sleep pattern been like? Has the child had short sleeps awaking crying or natural wakes and long sleeps?
- How much is the child drinking and eating and is it being tolerated?
- How many times have the child vomited, large/small amount, what happens after they have vomited?
- How many times has the child been to the toilet or wet nappies? When was the last stool passed?
- When were the last medication given and did it settle them? Do they feel the medication is working? or has the medication been changed? If so what to, by who and when?
- How is every one coping in the family?
Appendix Two: Dose ranges
The following examples are for guidance – dose ranges are included here for completeness but are not necessary to include in every SMP.

Doses are based on the APPM Master Formulary 2012

Pain
Non-pharmacological:
- Problem solve – eg trapped wind – consider how this might be resolved
- Re-positioning
- Use of equipment
- Relaxation – such as music, warmth and massage

Pharmacological:
1st line Oral non-opioids: Paracetamol
2nd line Oral opioids: if pain is not controlled with non-opioids, add oral Morphine as ‘Oramorph’ oral solution: give dose regularly every 4 hours plus use same dose for breakthrough. Suggested starting dose of:………………………………..

Note: For opioid naïve:
0-3 months: 50mcg/kg every 4 hours
3-6 months: 100mcg/kg every 4 hours
6 months – 12 years: 200mcg/kg every 4 hours (maximum starting dose 5mg)
12 years plus: 5-10mg every 4 hours

Dose adjustment: initially monitor response every 24 hours, may need to increase medication by up to 50-100% if pain control is poor (NB discuss with palliative care team)
Subsequently, adjust doses if more than 1-2 breakthrough doses needed on more than one day: add up total dose needed and divide by 6 to obtain new regular and breakthrough dose

Acute severe pain
Consider using small dose of Diamorphine solution buccally for acute pain and distress: dose can be repeated after 10 minutes – max 4x in 1 hour.
Dose:…………………………… (50-100mcg/kg max single dose 10mg)
This dose is based on weight and does not alter with regular medication

Parenteral opioids
Diamorphine can be given by CSCI. Starting dose of:………………………………over 24 hours. (If converting from oral Morphine, give 50% of total daily oral dose as Diamorphine over 24 hours. If starting opioids for first time give 0.2-0.3mg/kg over 24 hours, max starting dose 10mg/24hours)

For breakthrough, use buccal Diamorphine……………………… (5-10% total daily dose) as needed 1-4 hrly
Dose adjustment: monitor response every 24-48 hours, increase medication as needed by 25-33%.
Nausea and vomiting

Pharmacological:
Nausea and vomiting caused by intra-cerebral or gut pathology:
Cyclizine is the first choice
Oral dose of:  (1 month – 6 years: 0.5-1mg tds; 6-12 years: 25mg tds; 12 years plus: 50mg tds)
Oral medication may be poorly absorbed in the context of uncontrolled vomiting, consider a parenteral route to establish control
Rectal dose: (2-6 years: 12.5 mg tds; 6-12 years: 25mg tds; 1 years plus: 50mg tds)
Cyclizine may also be given as a CSCI at a starting dose of: (1-5 years: 3mg/kg over 24 hours – max 50mg/24 hours; 6-12 years: 75mg over 24 hours; 12 years plus: 150mg over 24 hours)
N&V caused by medication or metabolic abnormalities (e.g. renal or hepatic)
Consider Haloperidol
Oral dose of: (12 years plus: 1.5mg nocte, increasing to bd if necessary)
Haloperidol can also be given by CSCI at a starting dose of: (1 month-12 years: 25mcg/kg over 24 hours max starting dose 1.5mg over 24 hours)
NB Haloperidol may cause acute dystonia (antidotes are Benztropine or Diphenhydramine)

Seizures

Pharmacological:
Acute management of prolonged seizures:
For a prolonged seizure lasting for more than 5 minutes, Midazolam may be given buccally at a dose of: The dose may be repeated once if necessary (6 months – 1 year: 2.5mg; 1-5 years: 5mg; 5-10 years: 7.5mg; 10 years plus: 10mg)
Oral prophylaxis for recurrent seizures:
For recurrent seizures, consider starting a prophylactic antiepileptic e.g. Carbamazepine suggested starting dose of: (1 month – 12 years: 5mg/kg at night; 12 years plus: 100-200mg once or twice daily)
Dose may be increased slowly to max 5mg/kg tds for under 12s, 400mg tds for over 12s
Parenteral prophylaxis for recurrent seizures:
Midazolam can be given by CSCI at a suggested starting dose of: (Starting dose 1.2mg/kg over 24 hours)
Dose can be increased gradually until seizures are controlled, to a maximum of 100mg over 24 hours